Patients: Referral Patterns

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Contents

Abstract

This chapter examines referral patterns to a dedicated neurology-led cognitive disorders clinic located in a secondary care setting in terms of the numbers of patients seen over the period 2002–2016, referral sources (primary and secondary care), patient characteristics (age, gender, ethnicity, social class, handedness) and casemix in terms of diagnosis. Although referral numbers have increased over the 15-year period, the proportion receiving a diagnosis of dementia has fallen, which may indicate the persistence of a dementia diagnosis gap.

Keywords

Dementia · Demographics · Diagnosis · Referral patterns

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It is a truth universally acknowledged that dementia is a major global public health issue, set to increase as the world population ages (Ferri et al. 2005; World Health Organization 2012).

In 2010, a global cost of illness study suggested a "base case option" figure of US$604 billion, equivalent to the 18th largest national economy in the world at that time (between Turkey and Indonesia), and larger than the revenue of the world's largest companies (Wal-Mart, Exxon Mobil). In high income countries, which accounted for 89% of the costs but only 46% of dementia prevalence, this was mostly due to direct costs of social care, whilst in low and middle income countries, which accounted for only 11% of the costs but 54% of dementia prevalence, this was mostly due to informal care costs (Wimo and Prince 2010). By 2015 these costs had increased to an estimated US$818 billion, with 46 million people in the world living with dementia (Prince et al. 2015). Even if, as some data suggest, the age-specific incidence of dementia is declining in England and Wales, nevertheless because of the ageing of the population the numbers of people with dementia will continue to increase (Ahmadi-Abhari et al. 2017).

The need to address these issues is therefore obvious, from the human as well as the economic standpoint. This will require governments, individually and globally, to make dementia a priority, with the development of policies, investment in chronic care, and funding of research. It is heartening that some attempts have been made to develop such policies, both nationally (Department of Health 2009, 2012, 2015; Larner 2018) and internationally. A summit meeting of the G8 nations in London in December 2013 made a bold commitment to develop a cure or treatment for dementia by 2025 (Department of Health 2013).

Faced with such enormities, what can the individual clinician hope to contribute? The National Dementia Strategy (NDS) for England (Department of Health 2009) proposed three key themes to address the problem of dementia: improved awareness; early diagnosis and intervention; and a higher quality of care. Many of the 17 "key objectives" fell outwith the clinical domain, such as an information campaign to raise awareness and reduce stigma, and improvement in community personal support services, housing support and care homes. However, the early identification and appropriate initial management of dementia cases may be deemed to fall squarely within the remit of the individual clinician. The first issue to address, therefore, is the referral routes by which such patients arrive at the clinical encounter.

1.1 Referral Numbers

Referrals to the Cognitive Function Clinic (CFC) at the Walton Centre for Neurology and Neurosurgery (WCNN) in Liverpool represent a small but relatively complex caseload. Generally it may be said that the assessment and diagnosis of patients with memory complaints and/or cognitive disorders is ill-suited to the workings of general neurological outpatient clinics, partly for lack of adequate time to assess fully the history and cognitive performance of these patients. Longer cognitive screening instruments may have greater diagnostic accuracy (Sect. 6.1.3; Larner 2015a).

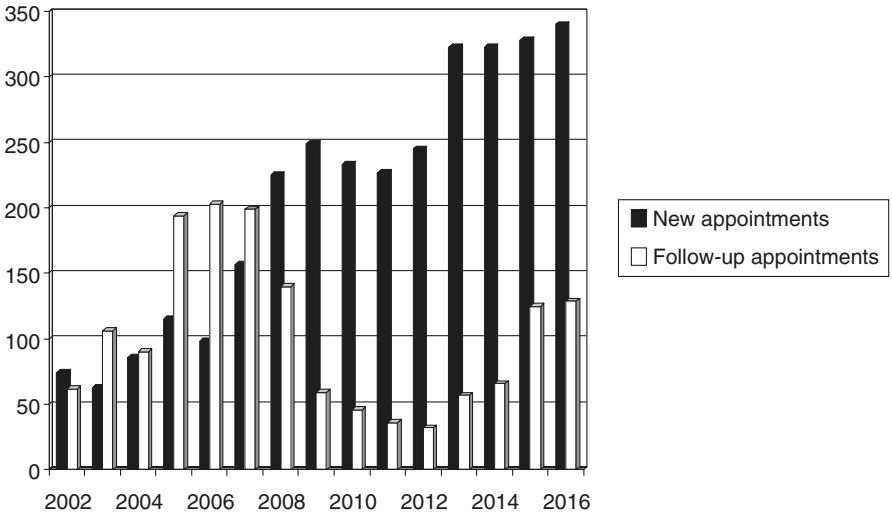

Fig. 1.1 Referral numbers to CFC, 2002–2016

Referral numbers to the author's clinic have gradually escalated over time (Fig. 1.1), which may possibly be a reflection of increasing public awareness of dementia. The 359% increase over the 15-year period 2002–2016 equates to an average increase of 23.9% per year, well ahead of the steady ~3% increase in general neurology outpatient numbers seen in the past decade. Patient numbers seen in 2008–2013 were more than twice those seen in 2002–2007, as reflected in recruitment for studies. For example, more patients were recruited in 6 months in 2013 than in 2 years in 2004–2006 in the analysis of primary care use of cognitive screening instruments (see below, Sect. 1.2.1, and Table 1.5 first two rows; for another example of doubled referral rate, see sequential studies on the "Attended alone" sign, Sect. 3.2.1).

To identify trends in the serial data, cumulative sum (cusum) points may be used (Wohl 1977). For annual CFC referrals over the decade 2007–2016, cusum points were calculated and plotted using the method of Kinsey et al. (1989), namely: selection of a reference point (the 2007 datum); subtraction of this reference point from successive recordings and the remainder added to the previous sum, with this cumulative sum plotted against time (Table 1.1; Fig. 1.2). Using this approach, if successive datapoints are the same as the reference point, the cusum plot remains at zero, if the successive datapoints rise (upward gradient) or fall (downward gradient) the cusum plot does likewise (Larner 2011:24–7;41–4). The upward gradient of the cusum plot of referrals to CFC is clearly seen (Fig. 1.2) reflecting an inexorable upward trend.

However, this increase may perhaps be contrary to the expectations of national policy documents such as the guidelines of the National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (NICE/SCIE 2006), which, requiring a "single point of referral" for all cases (de facto, old age psychiatry),

Table 1.1 Cusum points for CFC referrals, 2007–2016: reference point = 157 (2007 referrals)

Cumulative summed frequency			
Year	Referrals	Calculation	Cusum point
2007	157	157	0
2008	225	(225 − 157) + 157 = 225	+58
2009	249	(249 − 157) + 225 = 317	+160
2010	233	(233 − 157) + 317 = 393	+236
2011	227	(227 − 157) + 393 = 463	+306
2012	245	(245 − 157) + 463 = 551	+394
2013	323	(323 − 157) + 551 = 717	+560
2014	323	(323 − 157) + 717 = 883	+726
2015	328	(328 − 157) + 883 = 1054	+897
2016	340	(340 − 157) + 1054 = 1237	+1080

See Fig. 1.2

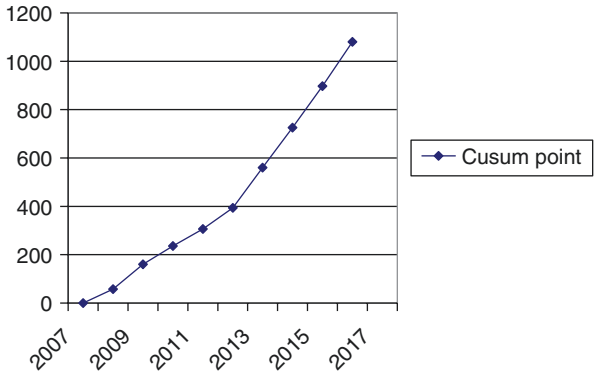

Fig. 1.2 Cusum plot: CFC referrals, 2007–2016

might have been anticipated to erode referrals to a neurology-led clinic. In fact, comparing the 2 years immediately before and after publication of the NICE/SCIE guidelines (Larner 2009a) there was a 79% increase in new referrals seen in CFC. Likewise, there was a 12% increase in the number of referrals comparing the 12-month periods immediately before and after the launch of the NDS (Larner 2010).

The fall off in numbers of follow-up appointments post 2008 (Fig. 1.1) was occasioned by the decommissioning of CFC prescriptions for cholinesterase inhibitors for financial reasons. It is possible that memory clinics may be no more effective than primary care practitioners for post-diagnosis treatment and coordination of care for dementia patients, as shown in a study from the Netherlands (Meeuwsen et al. 2012), although inevitably the cohort of patients readily available for clinical trials of novel drugs in the secondary care (Sect. 10.2.2) setting is reduced.

1.2 Referral Sources

The vast majority of referrals to CFC have come from three sources: primary care physicians (general practitioners), psychiatrists, and neurologists.

1.2.1 Primary Care

The majority of referrals to CFC have been initiated by general practitioners (GPs) working in primary care settings.

Initial studies examining referral sources found that around 50% came from primary care (Larner 2005a; Fisher and Larner 2007; Fearn and Larner 2009). This proportion increased to around 70% following publication of national directives (NICE/SCIE, NDS; Larner 2009a, 2010; Menon and Larner 2011; Table 1.2 penultimate row) and has remained consistently above this figure in subsequent studies (Ghadiri-Sani and Larner 2014; Wojtowicz and Larner 2015, 2016; Cannon and Larner 2016). These data suggest that awareness of the problem of dementia has increased amongst primary care clinicians over the past decade (see also Sects. 10.5.1 and 10.5.3).

A closer analysis of referrals has permitted referral source patterns to be addressed (Table 1.3; Fig. 1.3). In the 5-year period 2009–2013 the null hypothesis that the proportion of patients referred to CFC from primary care did not differ significantly was rejected ($\chi^2 = 22.1$, df = 4, $p < 0.001$; Larner 2014a). Extending the analysis to 8 years (2009–2016) resulted in the same outcome ($\chi^2 = 26.9$, df = 7, $p < 0.001$).

Table 1.2 Referral numbers, sources and diagnoses before and after launch of NICE/SCIE and NDS directives (adapted from Menon and Larner 2011; based on data from Larner 2005a; Fisher and Larner 2007; Menon and Larner 2011) reprinted with permission

	(Sept 2002 to August 2004)	Before NICE/SCIE launch (Oct 2004 to Sept 2006)	Before NDS launch (Feb 2008 to Feb 2009)	After NDS launch (Feb 2009 to Feb 2010)
New referrals seen	183	231	225	252
Dementia (% prevalence in cohort)	90 (49.2)	117 (50.6)	74 (32.9)	75 (29.8)
New referrals from primary care (% of total new referrals)	90 (49.2)	123 (53.2)	131 (58.2)	175 (70.2)
Primary care referrals with new diagnosis of dementia (% of primary care referrals)	36 (40.0)	45 (36.6)	28 (21.3)	42 (24.0)

Table 1.3 Referral numbers, sources and diagnoses, CFC 2009–2016 (adapted and updated from Larner 2014a; see Table 1.8 for a breakdown of sources of secondary care referrals)

Year	*N*	Referral source		Diagnosis		
		Primary care (%)	Secondary care (%)	Dementia (% of *N*)	No dementia (% of *N*)	MCI (% of *N*; % of no dementia)
2009	249	174 (70)	75 (30)	76 (31)	173 (69)	30 (12; 17)
2010	233	149 (64)	84 (36)	71 (30)	162 (70)	25 (11; 15)
2011	227	177 (78)	50 (22)	53 (23)	174 (77)	39 (17; 22)
2012	245	197 (80)	48 (20)	67 (27)	178 (73)	40 (16; 22)
2013	323	243 (75)	80 (25)	88 (27)	235 (73)	66 (20; 28)
2014	323	252 (78)	71 (22)	82 (25)	241 (75)	71 (22; 29)
2015	328	246 (75)	82 (25)	70 (21)	258 (79)	69 (21; 28)
2016	340	265 (78)	75 (22)	75 (22)	265 (78)	70 (21; 26)
Total (%)	2268	1703 (75.1)	565 (24.9)	582 (25.7)	1686 (74.3)	410 (18; 24)

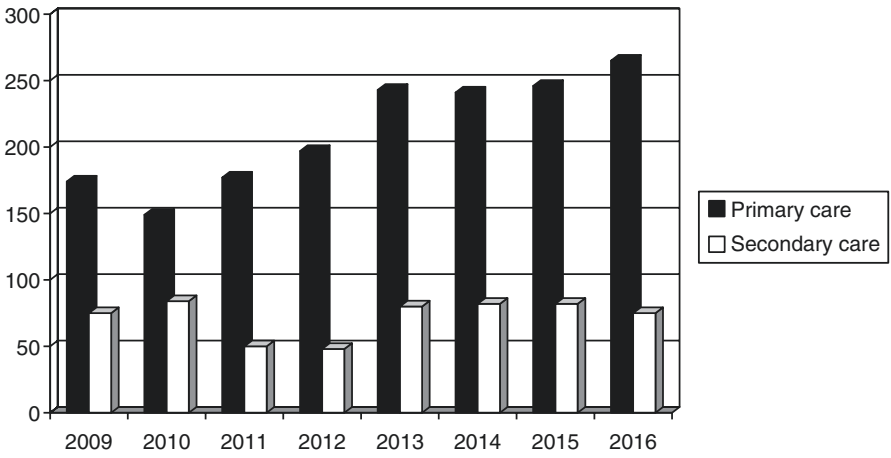

Fig. 1.3 Referral sources to CFC, 2009–2016

Cusum points (Kinsey et al. 1989; Sect. 1.1) for annual referrals to CFC from primary care were calculated and plotted with the 2009 datum selected as reference point (Table 1.4; Fig. 1.4). The upward trend of referrals to CFC from primary care in recent years is evident from the upward gradient of the cusum plot.

The frequency of dementia diagnosis has been consistently lower in the referral cohort from primary care than in patient groups referred from secondary care (Larner 2005a; Fisher and Larner 2007; Menon and Larner 2011; Table 1.2 bottom row). There is some evidence for increasing numbers of referrals of so-called "worried well" patients (for a discussion of this terminology, see Sect. 8.3) from primary care (Sect. 10.5.3). Whilst it is accepted that making a diagnosis of dementia or cognitive disorder is not the only function of CFC, and that reassurance of the "worried well" may be deemed an important clinical function, nonetheless establishing dementia diagnoses is key to the purposes of such clinics.

Table 1.4 Cusum points for annual referrals to CFC from primary care, 2009–2016: reference point = 174 (2009 referrals)

Cumulative summed frequency			
Year	Referrals from primary care	Calculation	Cusum point
2009	174	174	0
2010	149	(149 − 174) + 174 = 149	−25
2011	177	(177 − 174) + 149 = 152	−22
2012	197	(197 − 174) + 152 = 175	+1
2013	243	(243 − 174) + 175 = 244	+70
2014	252	(252 − 174) + 244 = 322	+148
2015	246	(246 − 174) + 322 = 394	+220
2016	265	(265 − 174) + 394 = 485	+311

See Fig. 1.4

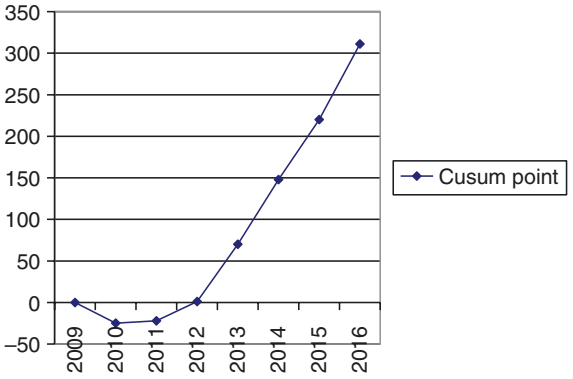

Fig. 1.4 Cusum plot: annual referrals to CFC from primary care, 2009–2016

Why should primary care referrals have the lowest "hit rate" for dementia diagnosis? It might be argued that with the possibility of longitudinal (i.e. intraindividual) patient assessment, GPs are well placed to detect cognitive change in their patients (Fisher and Larner 2006), unlike practitioners in secondary care who generally have to make a cross sectional (i.e. interindividual) assessment. Change in patient function might be suggested to primary care physicians by missed appointments, repeated phone calls on the same topic, and poor medication concordance. On the other hand, there has undoubtedly been a certain antipathy to making dementia diagnoses in primary care for various reasons, including therapeutic nihilism and lack of confidence related to inadequate training in this area (O'Connor et al. 1988; Audit Commission 2002) rather than any suggestion of intellectual turpitude. Failure to administer cognitive screening instruments (CSI; see Chap. 4) may also be a contributory factor.

Examination of referral letters from primary care physicians to CFC, looking for evidence of CSI use prior to referral, has been undertaken in several cohorts (Fisher and Larner 2007; Menon and Larner 2011; Cagliarini et al. 2013; Ghadiri-Sani and Larner 2014; Wojtowicz and Larner 2015, 2016; Cannon and Larner 2016;

Table 1.5 Cognitive screening instrument (CSI) use reported in primary care referrals to CFC (adapted from Wojtowicz and Larner 2015; based on data from Fisher and Larner 2007; Menon and Larner 2011; Cagliarini et al. 2013; Ghadiri-Sani and Larner 2014; Cannon and Larner 2016; Bharambe and Larner 2018)

Period	Oct 2004 to Sept 2006	Feb 2008 to Feb 2009	Feb 2009 to Feb 2010	July to Dec 2012	July to Dec 2013	Jan to Dec 2015	April to Oct 2017
N (% of all referrals to CFC)	123 (53.2)	131 (58.2)	175 (70.2)	99	140 (75.7)	246 (75.0)	127 (75.1)
Any CSI used (% of *N*)	25 (20.3)	34 (25.9)	47 (26.8)		44 (31.4)	93 (37.8)	65 (51.1)
CSI use:							
MMSE	17	31	29		13	30	27
AMTS	6	2	11		6	4	2
CDT	1	0	0		0	1	0
6CIT	1	0	2	7	8	38	24
GPCOG	0	0	1		13	22	10
MoCA	0	0	0		0	3	4
Equivocal	0	1	6 (NB: 2 tests reported in 2 patients)		4	1 (NB: 2 tests reported in 6 patients)	0 (NB: 2 tests reported in 2 patients)

N number of referrals from primary care, *MMSE* Mini-Mental State Examination, *AMTS* Abbreviated Mental Test Score, *CDT* Clock drawing test, *6CIT* Six-Item Cognitive Impairment Test, *GPCOG* General Practitioner Assessment of Cognition, *MoCA* Montreal Cognitive Assessment

Bharambe and Larner 2018). For example, in two 2-year cohorts, covering the periods October 2004 to September 2006 (Fisher and Larner 2007) and February 2008 to February 2010 (Menon and Larner 2011; Tables 1.2 and 1.5), the initial study found that in 20.3% of GP referrals (25/123) a specific CSI was mentioned, whereas in the second study this had risen to 26.5% (81/306), a change which did not permit rejection of the null hypothesis ($\chi^2 = 1.54$, df = 1, $p > 0.1$).

The latter 2-year cohort bridged the launch of the National Dementia Strategy (Department of Health 2009). Comparing the 12 month periods pre- and post-NDS launch there was a small increase in reported CSI use (34/131, 25.9% vs. 47/175, 26.8%; Table 1.5) but this did not reach statistical significance ($\chi^2 = 0.07$, df = 1, $p > 0.5$; Menon and Larner 2011).

The CSIs most commonly used in these observational surveys of primary care practice were initially the Mini-Mental State Examination (MMSE; Folstein et al. 1975) and the Abbreviated Mental Test Score (Hodkinson 1972). This practice may have reflected the longevity of these instruments, and/or their recommendation in *Understanding dementia. A resource pack for GPs and patients* which was issued in support of the NDS (Department of Health/Alzheimer's Society 2009).

There are, of course, a very large number of CSIs described in the literature (see, for example, Larner 2017), some of which have been developed specifically for use in primary care and are therefore recommended in this setting (Brodaty et al. 2006; Cordell et al. 2013). These include the Six-Item Cognitive Impairment Test (6CIT; Brooke and Bullock 1999; Gale and Larner 2017), the Memory Impairment Screen (MIS; Buschke et al. 1999), Mini-Cog (Borson et al. 2000), and the General Practitioner Assessment of Cognition (GPCOG; Brodaty et al. 2002; Seeher and Brodaty 2017). These CSIs were very seldom mentioned, if at all, in the initial CFC surveys (Larner 2005a; Fisher and Larner 2007; Menon and Larner 2011), suggesting they had not displaced the older tests (Table 1.5).

An audit of dementia referrals to a later life psychiatry service reported that only 13.2% of referral letters contained MMSE results (Hussey et al. 2009), commensurate with the empirical findings in CFC (Fisher and Larner 2007; Menon and Larner 2011), and in marked contrast with the (widely cited) findings reported from a postal survey which claimed 79% use of CSIs in three English Primary Care Trusts (Milne et al. 2008). Since it would seem unlikely that GPs fail to report MMSE or other CSI results in referral letters to dedicated dementia services if these tests have been undertaken in primary care (at least as a systematic, as opposed to an occasional, omission), the discrepancy might be accounted for by MMSE being too time consuming in primary care, and/or too difficult to interpret (Larner 2009b).

More recent surveys of primary care referrals to CFC (Cagliarini et al. 2013; Ghadiri-Sani and Larner 2014; Wojtowicz and Larner 2015, 2016; Cannon and Larner 2016; Bharambe and Larner 2018) have suggested increased use of CSIs appropriate for administration in primary care, specifically 6CIT and GPCOG (Table 1.5, three right-hand columns). However, despite an increase in overall CSI usage (approaching 40% in the 2015 cohort) the null hypothesis that the proportion of CSI use in primary care patients in the first four sequential cohorts did not differ significantly was not rejected ($\chi^2 = 3.94$, df = 3, $p > 0.1$; Ghadiri-Sani and Larner 2014). Looking specifically at use of GPCOG (Wojtowicz and Larner 2015), the null hypothesis that the proportion of GPCOG use in primary care referrals did not differ significantly between the 2015, 2013, and the summed previous cohorts was rejected ($\chi^2 = 41.1$, df = 2, $p < 0.001$).

Despite evidence of increasing CSI usage in primary care, this may not necessarily provide unequivocal and hence potentially useful diagnostic information, since errors in the scoring and reporting of CSIs administered in primary care were found in around one-quarter of cases. Both 6CIT and GPCOG, CSIs specifically recommended for use in primary care, were particularly liable to scoring errors (Cannon and Larner 2016; Wojtowicz and Larner 2016; Fig. 1.5).

Does primary care CSI use vary according to the final CFC diagnosis? In the study of Cannon and Larner (2016), the proportions of patients with diagnoses of dementia or no dementia (=mild cognitive impairment [MCI] + subjective memory complaint [SMC]) who had been assessed with CSIs in primary care were 16/52 (=30.8%) and 77/194 (=39.7%) respectively. The null hypothesis that the proportion

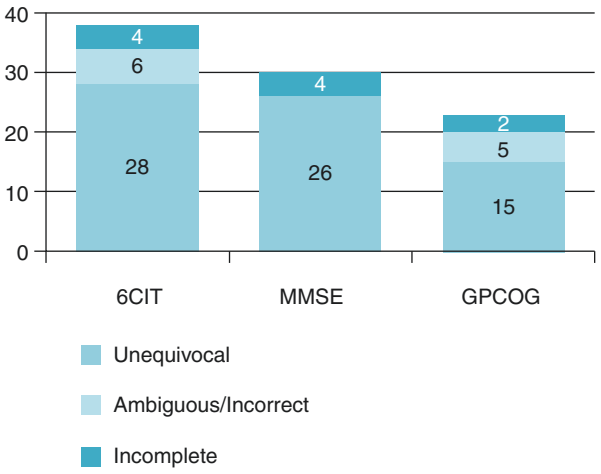

Fig. 1.5 Frequency of scoring/reporting errors for different CSIs administered in primary care (adapted from Wojtowicz and Larner 2016; error classification categories of Wojtowicz and Larner 2015)

Table 1.6 Comparison of primary care CSI use by final diagnosis in two patient cohorts

Period	July to December 2013	January to December 2015
Reference	Ghadiri-Sani and Larner (2014)	Cannon and Larner (2016)
N	140	246
Prevalence: Dementia; MCI	0.24, 0.13	0.21, 0.20
Proportion of dementia vs. non-dementia patients (MCI + SMC) assessed with CSI	12/34 (=35.3%) vs. 32/106 (=30.2%); $\chi^2 = 0.18$, df = 1, $p > 0.5$	16/52 (=30.8%) vs. 77/194 (=39.7%); $\chi^2 = 1.65$, df = 1, $p > 0.1$
Proportion of any cognitive impairment (dementia + MCI) vs. no cognitive impairment (SMC) patients assessed with CSI	17/52 (=32.7%) vs. 27/88 (=30.7%); $\chi^2 = 0.14$, df = 1, $p > 0.5$	35/100 (=35%) and 58/146 (=39.7%); $\chi^2 = 0.64$, df = 1, $p > 0.1$

of demented and non-demented patients assessed in primary care with a CSI did not differ significantly was not rejected ($\chi^2 = 1.65$, df = 1, $p > 0.1$). The proportions of cognitively impaired (dementia + MCI) and cognitively unimpaired (=SMC) patients who had been assessed with a CSI in primary care were 35/100 (=35%) and 58/146 (=39.7%) respectively. The null hypothesis that the proportion of cognitively impaired and cognitively unimpaired patients assessed in primary care with a CSI did not differ significantly was not rejected ($\chi^2 = 0.64$, df = 1, $p > 0.1$). These figures were similar to those observed in the prior study by Ghadiri-Sani and Larner (2014), as shown in Table 1.6. However, Bharambe and Larner (2018) found a trend towards patients with functional cognitive disorders (see Sect. 8.3) being more likely to have had a cognitive screening instrument administered prior to referral than those with a cognitive disorder ($\chi^2 = 3.41$, df = 1, $0.1 > p > 0.05$).

1.2.2 Psychiatry

Behavioural and neuropsychiatric symptoms (BPSD) are not uncommon in dementia syndromes (see Sect. 8.2.1). Dementia as a syndrome transcends the professional boundaries of neurology and psychiatry and it is therefore not surprising that both disciplines should be involved in patient diagnosis and management (see Sect. 10.6).

Analysis of referrals to CFC over a 5-year period (September 2002 to August 2007; Larner 2007a) showed that 21.3% of referrals (95% CI = 17.8–24.8%) came directly from either general or old age psychiatrists (Table 1.7, left hand column). Of these, 58.8% received a diagnosis of dementia (95% CI = 49.7–67.8%). The most common dementia subtypes were Alzheimer's disease (36) and frontotemporal lobar degenerations (FTLD; 20). Informal comparison of these data with an unselected (partially overlapping) cohort of consecutive patients previously reported from CFC (Table 1.7, right hand column; Larner 2005b) indicated that the patients referred by psychiatrists were of similar age but had a higher frequency of dementia (58.8% vs. 50.6%), particularly FTLD (29.8% vs. 12.5%). These data suggested that psychiatrists use neurological services to assist with the diagnosis of dementia, and hence presumably value this referral option, particularly in the case of individuals with suspected dementia of early-onset and of FTLD type.

The NICE/SCIE guidelines (2006) regarding the identification, treatment and care of people with dementia anticipated that psychiatrists, particularly old age psychiatrists, would manage the dementia care pathway in its entirety from diagnosis to end-of-life care. A "single point of referral" was specified in the guidelines. These recommendations apparently ignored the fact that some neurologists and geriatricians had developed significant specialist interests in dementia. Compliance with NICE/SCIE guidelines might have been anticipated to erode the number of general referrals to neurology-led memory clinics, and referrals to these clinics from psychiatrists in particular. However, a study in CFC (see Sect. 10.5.1; Table 10.2) in

Table 1.7 Referrals from psychiatrists to CFC: demography and diagnoses (adapted from Larner 2007a)

	Referrals from psychiatrists (September 2002 to August 2007)	All referrals (February 2002 to January 2004) (data from Larner 2005b)
N	114	158
Prevalence dementia	0.59	0.51
F:M (% female)	53:61 (46.5%)	69:89 (43.7%)
Age range in years	42–81 (mean 63.4 ± 8.6)	49–84 (mean 64.5 ± 8.2)
Dementia subtypes		
Alzheimer's disease	36	62
Frontotemporal dementias	20	10
Vascular dementias	4	4
Others	7	4

Table 1.8 Referral numbers from secondary care to CFC 2009–2016

Year	*N*	Referral source		
		Psychiatry (% of *N*)	Neurology (% of *N*)	Other (% of *N*)
2009	75	30 (40)	33 (44)	12 (16)
2010	84	36 (43)	37 (44)	11 (13)
2011	50	27 (54)	14 (28)	9 (18)
2012	48	22 (46)	11 (23)	15 (31)
2013	80	30 (38)	24 (30)	26 (32)
2014	71	22 (31)	26 (37)	23 (32)
2015	82	32 (39)	26 (32)	24 (29)
2016	75	36 (48)	19 (25)	20 (27)
Total (%)	565	235 (41.6)	190 (33.6)	140 (24.8)

fact showed a large increase in referral numbers to CFC comparing the 2-year periods immediately before (January 2005 to December 2006) and after (January 2007 to December 2008) publication of the NICE/SCIE document (Larner 2009a).

An analysis of referrals to CFC from secondary care also addressed this issue (Table 1.8). About 40% of such referrals come from psychiatrists. The null hypothesis that the proportion of patients referred from secondary care by psychiatrists to CFC over the 8-year period 2009–2016 did not differ significantly was not rejected ($\chi^2 = 9.14$, df = 7, $p > 0.1$); likewise, referrals from psychiatrists as a proportion of all referrals to CFC, although a trend was observed ($\chi^2 = 12.75$, df = 7, $0.1 > p > 0.05$).

1.2.3 Neurology

A sizeable number of secondary care referrals to CFC comes from other neurologists (Table 1.8), mostly colleagues at WCNN but sometimes from further afield. These neurological referrals have the highest percentage of dementia diagnoses, compared to referrals from primary care and from psychiatrists (Larner 2005a), a possible indication of the "added value" to be gained from neurological referral. (The added value of neurological referral has, perhaps counterintuitively from the perspective of neurologists, been difficult to demonstrate; Association of British Neurologists 2002.) Neurologists may also refer from their own area of subspecialist interest patients who may have cognitive impairment as one feature of their neurological illness (Larner 2008, 2013a; Larner et al. 2011).

1.3 Referral Demographics

1.3.1 Patient Age

With its historic focus on early-onset dementias (Ferran et al. 1996), it is inevitable that the patients referred to CFC are generally younger than those seen in old age psychiatry and geriatric memory clinics. (It is generally recognised that patients

with dementia included in clinical research studies are systematically younger than patients from the general population; Schoenmaker and Van Gool 2004.) Although dementia prevalence increases with age, the differential diagnosis of cognitive impairment in younger people is recognised to be much broader (Doran 1997; Rossor et al. 2010; Davies et al. 2011). Numbers of patients with early-onset dementia are thought to be higher than previously recognised (Alzheimer's Society 2014).

Typically the mean or median age of patients referred to CFC has been in the late 50s to early 60s, with a broad age range from around 20 to 90 years (e.g. see Table 1.7, and data from a number of pragmatic diagnostic test accuracy studies in consecutive new patient referrals detailed in Chap. 4). This age structure does not seem to have changed noticeably during the period over which these studies have been undertaken in CFC.

In a cohort of patients seen over a 1-year period (July 2012 to June 2013; $N = 269$; Price and Larner 2013), 177 (=65.8%) were aged ≤65 years, of whom 24 had dementia (=13.6%) and another 33 (=18.6%) had cognitive impairment but were not demented, whereas 78/92 (=84.7%) older patients had either dementia (57) or cognitive impairment but not dementia (21). Hence the relative risks or risk ratios of any cognitive impairment, of dementia, or of cognitive impairment short of dementia in young patients compared to old were 0.38 (95% CI = 0.17–0.59), 0.22 (95% CI = −0.12–0.56), and 0.82 (95% CI = 0.58–1.05) respectively.

Correlations between patient age and scores on a number of the CSIs examined in CFC (see Chap. 4) are shown in Table 1.9. Diagnostic performance of investigations may be influenced by patient age, for example some neurological signs (see Sect. 3.2.1, Fig. 3.2) and CSIs (Sect. 6.1.5; Wojtowicz and Larner 2017).

Table 1.9 Summary of correlation coefficients for selected cognitive screening instruments examined in CFC and patient age (adapted and updated from Larner 2015b:75)

	r	Performance	*t*	*p*
MMSE	−0.23	No	3.63	<0.001
MMP	−0.26	No	4.06	<0.001
ACE-R	−0.32	Low	4.47	<0.001
MACE	−0.31	Low	7.96	<0.001
6CIT	0.33	Low	5.55	<0.001
MoCA	−0.34	Low	5.84	<0.001
s-MoCA	−0.40	Low	7.01	<0.001
TYM	−0.30	Low	4.61	<0.001
H-TYM	−0.37	Low	2.37	<0.02
Free-Cog[a]	−0.31	Low	1.37	>0.1
AD8	0.02	No	0.28	>0.5

Negative correlation with age = lower test scores worse
Positive correlation with age = higher test scores worse (i.e. test negatively scored)
MMSE Mini-Mental State Examination, *MMP* Mini-Mental Parkinson, *ACE-R* Addenbrooke's Cognitive Examination-Revised, *MACE* Mini-Addenbrooke's Cognitive Examination, *6CIT* Six-Item Cognitive Impairment Test, *MoCA* Montreal Cognitive Assessment, *s-MoCA* Short Montreal Cognitive Assessment, *TYM* Test Your Memory test, *H-TYM* Hard Test Your Memory test
[a]Preliminary data

1.3.2 Patient Gender

Meta-analyses of dementia prevalence studies suggest that dementia is more prevalent in women, mostly due to the increasing prevalence of Alzheimer's disease with age, whilst vascular dementia is more common in men (Lobo et al. 2000). Local studies have also suggested the influence of female gender on Alzheimer's disease incidence (Copeland et al. 1999:435). The appropriate population for dementia screening might be anticipated to show a slight female predominance (hence all the CFC studies tabulated in this book give the proportion of female patients in each cohort).

Regarding patient gender in referrals to CFC, typically there has been a slight preponderance of males (Table 1.10; Fig. 1.6a), in contrast with general neurology clinics where females are in the majority (Larner 2011:27, 43–5; Fig. 1.6b). For example, in a 3-year study (September 2008 to August 2011), a total of 726 new patients was assessed in CFC of whom 52.8% were male (F:M = 343:383; Larner 2014b). Consistently, pragmatic diagnostic test accuracy studies of neurological signs and CSIs undertaken in consecutive patient cohorts (Chap. 4) have recruited more men than women, with only rare exceptions (e.g. Larner 2007b, 2012a).

Diagnostic performance of neurological signs may be influenced by patient gender (see Sects. 3.2.1 and 3.2.2, and Fig. 3.1).

1.3.3 Patient Ethnicity and Social Class

Details on patient ethnicity and social class have not been collected in CFC studies. However, using the 2001 UK Census groupings for ethnicity, the vast majority of patients referred (estimated to be >95% of total) fall within the White (British; Irish; Other) codes, with only small numbers (estimated to be <5% of total) falling within the Mixed, Asian or Asian British, Black or Black British, and Other ethnic groups codes.

Table 1.10 Referral numbers by patient gender, CFC 2009–2016

		Gender		
Year	*N*	Female	Male	% female
2009	249	110	139	44.2
2010	233	109	124	46.8
2011	227	117	110	51.5
2012	245	122	123	49.8
2013	323	141	182	43.7
2014	323	166	157	51.3
2015	328	156	172	47.6
2016	340	165	175	48.5
Total	2268	1086	1182	47.9

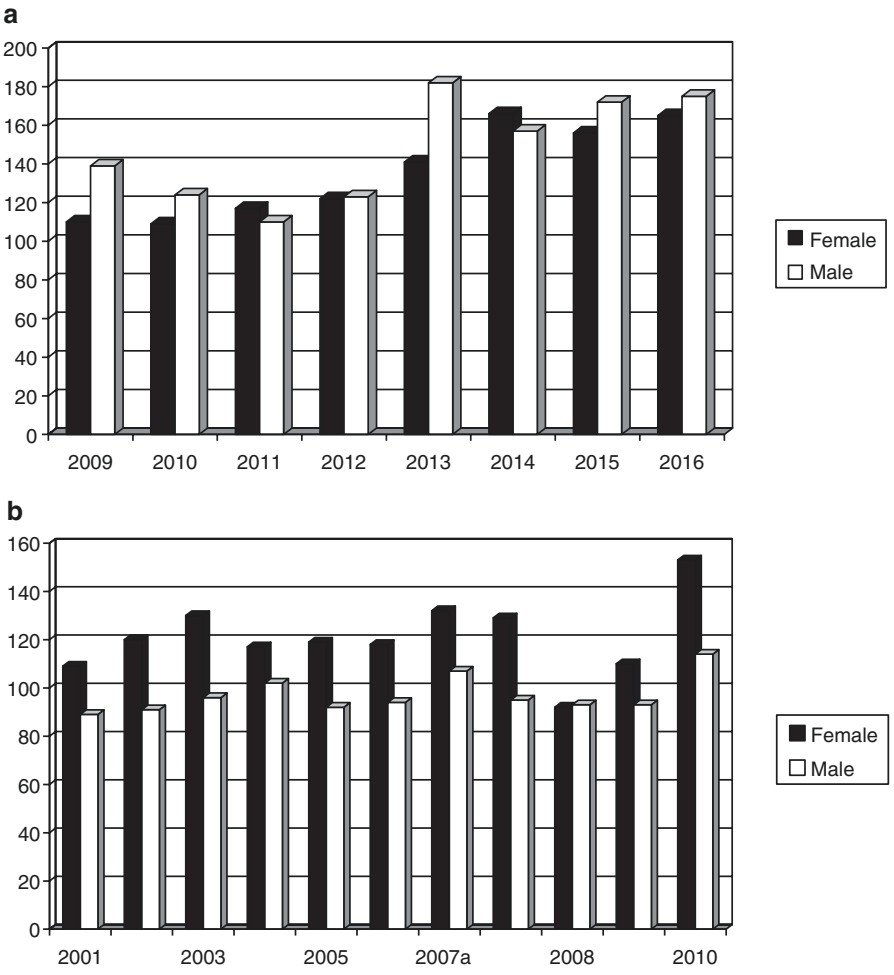

Fig. 1.6 Referrals by patient gender to (**a**) CFC, annual cohorts 2009–2016; and (**b**) the author's general neurology clinics, 3 month cohorts 2001–2010 (two cohorts in 2007). Graph b based on data in Larner 2011 "reprinted with permission"

1.3.4 Patient Handedness

Details on patient handedness have not been routinely collected in CFC studies, with the exception of the study on the mini-Addenbrooke's Cognitive Examination (MACE; Sect. 4.1.5.5; e.g. Larner 2015c).

Over a 3-year period, of 599 (F:M = 280:319) patients tested with MACE a total of 73 (=12.2%) were left-handed. Of these patients, 26/280 females were left-handed (=10.2%), and 47/319 males (=14.7%). These figures (Williamson and Larner 2018) are comparable with reference data: McManus (2009:45) reported an overall figure of 12.24% for left-handedness in the UK, and that

around 11–12% of men and 9–10% of women are typically left-handed in Western countries.

1.4 Casemix: Dementia Prevalence

The casemix of referrals to CFC shows marked clinical heterogeneity. This is, of course, the idiom of clinical practice, which is rather alien to the common methodology (Chap. 2) of assessing the utility of cognitive and non-cognitive screening instruments (Chaps. 4 and 5) which is usually based on the examination of selected diagnostic groups, and sometimes with normal control groups (see Sect. 2.3), so-called proof-of-concept (or phaseI/II; Sackett and Haynes 2002) studies.

There has been a decline over the years in the percentage of referred patients who have received a dementia diagnosis (see, for example, Table 1.2, row 2). Dementia prevalence was higher in the cohort assessed with the Addenbrooke's Cognitive Examination (n = 285; February 2002 to August 2005; 49%; Larner 2007c), compared to the cohort assessed with the Addenbrooke's Cognitive Examination-Revised (n = 243; August 2005 to August 2008; 35%; Larner 2009c, 2013b), and the cohort assessed with the Montreal Cognitive Assessment (n = 150; September 2009 to March 2011; 24%; Larner 2012b), and the cohort assessed with the mini-Addenbrooke's Cognitive Examination (n = 599; June 2014 to May 2017; 16.5%; Williamson and Larner 2018). A less rigorous comparison, but which nevertheless supports this conclusion, was provided by retrospective (2001–2002) and prospective cohorts (2010) evaluated with a test of visuoperceptual function, the Poppelreuter figure (Sect. 4.2.3), in which dementia prevalence was 56% and 28% respectively (Sells and Larner 2011).

This fall in dementia prevalence in clinic attenders may reflect increased referral of those non-demented individuals who may be variously described as "worried well", "subjective memory complainers", or be diagnosed with subjective memory complaint or impairment, particularly from primary care (see Sects. 1.2.1 and 10.5.3; also Sect. 3.2.1 for another example of the falling prevalence of dementia in clinic referrals over time). A similar pattern of increased referral of "benign memory complaints" has been reported from other clinics (Blackburn et al. 2014). However, it might also be reflective of earlier referral and identification of neurodegenerative disorders at the mild cognitive impairment stage before a dementia diagnosis is reached, a potentially important change in terms of case ascertainment and early deployment of disease-modifying therapy. Alternatively, many of these patients may have functional cognitive disorders (Stone et al. 2015; Bharambe and Larner 2018; see Sect. 8.3).

Analysis of referrals in the 8-year period 2009–2016 permitted diagnostic frequencies of dementia and mild cognitive impairment (MCI) to be examined (Table 1.3; Fig. 1.7). The null hypotheses that the proportions of all patients referred to CFC with either dementia ($\chi^2 = 12.45$, df = 7, $0.1 > p > 0.05$) or cognitive impairment (=dementia + MCI; $\chi^2 = 6.09$, df = 7, $p > 0.1$) over this period did not differ significantly were not rejected, confirming the findings of a prior 5-year analysis (Larner 2014a).

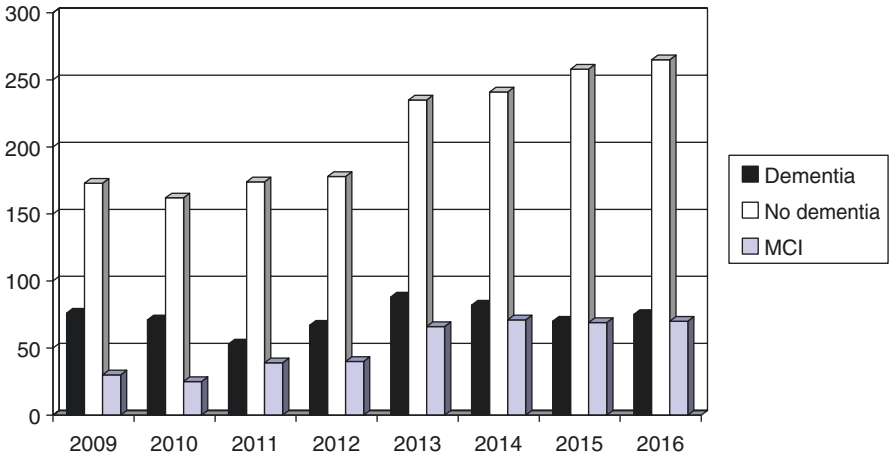

Fig. 1.7 Diagnostic frequencies of dementia, no dementia, and mild cognitive impairment, 2009–2016

Table 1.11 Cusum points for dementia diagnoses in CFC referrals, 2009–2016: reference point = 76 (2009 referrals)

Cumulative summed frequency			
Year	Dementia diagnoses	Calculation	Cusum point
2009	76	76	0
2010	71	(71 − 76) + 76 = 71	−5
2011	53	(53 − 76) + 71 = 48	−28
2012	67	(67 − 76) + 48 = 39	−37
2013	88	(88 − 76) + 39 = 51	−25
2014	82	(82 − 76) + 51 = 57	−19
2015	70	(70 − 76) + 57 = 51	−25
2016	75	(75 − 76) + 51 = 50	−26

See Fig. 1.8

Cusum points (Kinsey et al. 1989; Sect. 1.1) for dementia diagnoses in CFC referrals were calculated and plotted with the 2009 datum selected as reference point (Table 1.11; Fig. 1.8). The downward trend of referrals to CFC receiving a diagnosis of dementia is clearly seen from the downward gradient of the cusum plot.

Hence there is a paradox of more referrals (Figs. 1.1 and 1.2) but with fewer dementia diagnoses (Fig. 1.8) in CFC, and this despite rising numbers of dementia diagnoses nationally according to figures from the Health and Social Care Information Centre (http://www.hscic.gov.uk/article/4902/Number-of-patients-with-recorded-diagnosis-of-dementia-increases-by-62-per-cent-over-seven-years (last accessed 27/12/2017)).

Most dementia diagnoses have been of Alzheimer's disease and frontotemporal lobar degenerations (e.g. Table 1.7). Although cerebrovascular disease may be a recognised comorbidity in Alzheimer's disease, particularly in older patients,

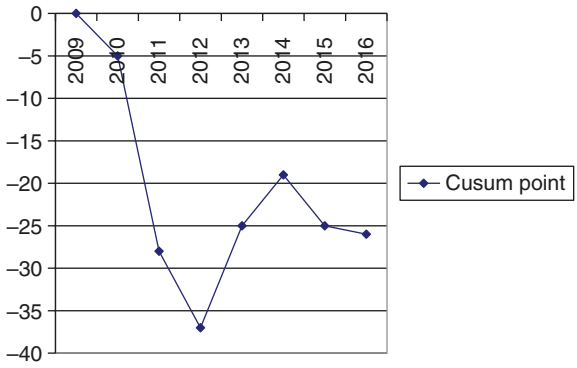

Fig. 1.8 Cusum plot: dementia diagnoses in CFC referrals, 2009–2016

patients with pure vascular dementia and vascular cognitive impairment have rarely been seen in CFC (see Sect. 9.4), likewise dementia with Lewy bodies and Parkinson's disease dementia (see Sect. 9.3). It may be that cases within the latter two categories are seen in dedicated stroke and movement disorder clinics respectively within WCNN, or may possibly be more likely to be referred directly to old age psychiatry and/or geriatric services.

1.5 Summary and Recommendations

Referrals to CFC of individuals with cognitive complaints have increased in number over the past decade, most particularly referrals from primary care. If this trend is mirrored in neurological services elsewhere, then it may well be that neurologists will be increasingly called upon to assess such patients, rather than relying on, or redirecting them to, old age psychiatry or geriatric services. The increase in referrals may reflect increased societal awareness of the problem of dementia and the importance of early diagnosis. However, there has been no increase in the proportion of patients diagnosed with dementia or cognitive impairment, and hence no evidence for closure of the dementia diagnosis gap (see Sects. 10.5.3, 10.5.4, and 10.5.5). Nevertheless, the retention and further development of neurology-led memory clinics, integrated with other services involved in the management of cognitive problems (see Sect. 10.6), would seem to remain both necessary and appropriate.

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